Child Life on the Palliative Care Team

The role, the reach, and the human stories behind the work

Loren Mirsky Piatkin | M.S., CCLS, GC-C, GCCA-C
Certified Child Life Specialist | Certified Grief Counselor

What Is a Child Life Specialist?

- Master's-level clinicians trained in child development, family systems, psychosocial care, and death and dying
- Certified through the Association of Child Life Professionals (ACLP)
- Embedded in pediatric hospitals — primarily in North America, but growing internationally
- Not therapists, not nurses — a distinct discipline focused on coping, communication, and meaning-making
- In palliative care: we sit at the intersection of the child, the family, and the team

"We help children and families find their footing when the ground shifts."

Where Child Life Fits on the Palliative Care Team

Medicine	Nursing	Social Work	Chaplaincy	Child Life
Disease management, symptom control & pain management	Physical care & daily comfort	Family systems & practical needs	Spiritual care & ritual	Psychosocial care coping & legacy

Child Life bridges the child's inner world with the care team's work.

Our roles span: Play & Normalization · Procedural Support · Psychosocial Care · Family Support · Sibling Support · Legacy & Memory Making · Bereavement

Play & Normalization: The Backbone of Child Life

Play transcends language.

Play is not a reward for good behavior or a distraction from hard things.
It is how children process their world — including illness, fear, and loss.

Therapeutic play

Using play to help children process medical experiences, express fears, and regain a sense of control

Medical play

Letting children handle equipment, practice on dolls, ask questions — demystifying the hospital environment

Expressive arts

Drawing, painting, music, movement — languages that bypass what words can't always reach

Normalization

Keeping childhood alive inside the hospital — daily schedules, walks around the ward, room decorating, celebrations

In the ICU: daily schedules · ward walks · art · floor play · board & card games · bubbles · room decorating · birthday celebrations

Procedural Support & Preparation and Psychosocial Care

Procedural Support & Preparation

- Honest, age-appropriate preparation before procedures
- Distraction and coping support during painful or frightening procedures
- Debriefing and normalization after — what the child experienced matters
- Reducing traumatic medical experiences that children carry forward

Psychosocial Care

- Meeting the child where they are — developmentally, emotionally, culturally
- Honest, developmentally appropriate communication about illness and death
- Supporting siblings — age-appropriate inclusion and their own space to process
- Supporting the child's sense of identity and control through illness
- Providing emotional support to caregivers — including active listening

Family & Caregiver Support

We don’t treat just the patient in the bed, we treat the whole family, holistically

From the CICU

Three mothers — each with a baby who had spent 9 to 11 months in the CICU. All had shared their frustration, pain, and sadness. I got permission to use a brick courtyard outside the hospital. I laid a sheet on the ground, brought pans of paint and fly swatters, and invited them to dip and slap.

They laughed. They cried. They made something together. Play is not only for children.

Coaching caregivers

How to talk to their child about illness and death — honestly, without overwhelming them

End-of-life preparation

Supporting families in shaping how the final days and moments are spent

Sibling Support: The Forgotten Griever

Siblings are often the most invisible members of the family in a palliative care setting — pulled from their routines, their needs deprioritized, their grief frequently unwitnessed.

From the ICU — Disney World

A six-year-old girl — a heart transplant patient in rejection — arrived at our hospital on ECMO after becoming critically ill on her Make-A-Wish trip to Disney World. She never made it to the park. Her parents and three brothers were with her, and it was clear she wasn't going to survive.

We rolled out a long sheet of paper on the floor. Each brother stepped into paint and walked the length of the paper, leaving their footprints. Then, together as a family, they added their sister's footprints alongside theirs.

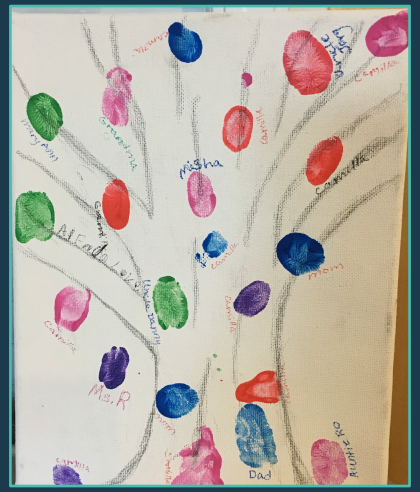
She was part of their story. And they were part of hers.

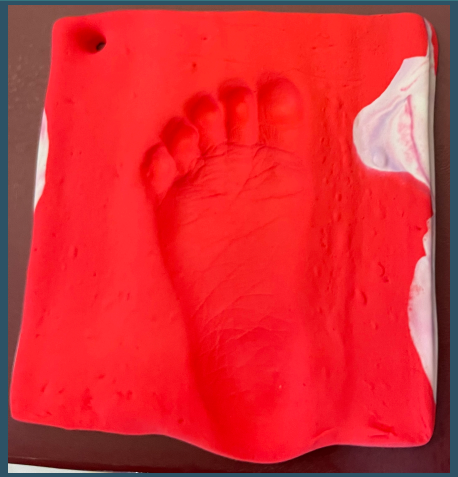
What siblings need: honest information · a role in the process · space to grieve their way

Memory Making & Legacy Building

Creating something tangible from a life — for the people left behind.

- Handprints, footprints, molds, casts
- Photography — professional and family-led
- Art projects — canvas, paint, mixed media
- Memory boxes: objects, fabrics, letters
- Audio and video recordings
- Books, journals, legacy letters
- Hair, scent, tactile keepsakes
- Experiences — curated moments before death


Mysha
Dad



Story: A Life Outside the CICU

A baby boy spent his entire nine months of life in the Cardiac ICU. His parents had initially refused palliative care — but over time, as it became clear he would not survive, they opened to it.

His mother's wish was simple: he had never been outside. Never felt grass. Never touched a living thing beyond the walls of his room.

We worked with the hospital to make it happen. Security blocked off the garden for a few hours. Privacy screens went up. The landscaping company donated lilies in pots — the mother's request — and placed them on the grass. A blanket was laid down. A respiratory therapist came with us to manage his support. And his mom and I smuggled in a rabbit wearing a tiny superhero cape.

I was the photographer. Parents placed his hands in the grass. They brought the rabbit to him. The sun was shining. There was a breeze. His parents lay beside him on the blanket.

When they were ready, the respiratory therapist turned off the ventilator. Slowly, peacefully, he died outside — in the sun, with his parents next to him.

They carried him back upstairs themselves.

Cultural Humility in Memory Making

Cultural humility is not a checklist. It is an orientation — toward curiosity, restraint, and genuine respect for what a family holds sacred.

01

Ask before offering

Not every family wants handprints. Not every tradition allows the taking of a lock of hair. Lead with questions, not assumptions.

02

Follow the family's cues

Sometimes the most important thing you can offer is silence, presence, or a small practical gesture — not a structured project.

03

Know your own lens

We each carry cultural assumptions about death, dying, and palliative care. Acknowledge them privately — then set them aside. This moment belongs to the family.

Stories: Culture Shapes the Work

Qatar — A Lebanese Family

A cardiac patient, four to six months in the CICU. Both parents were art majors. Every morning they asked: what are we making today? We worked on stretched canvas — handprints, footprints, layered paint — each piece decided by the parents. The canvases were displayed in the room. Mom carried guilt about waiting years to have a baby; she worried the delay had caused his illness. I listened. I didn't fix. The art gave us a way to connect, no words needed.

Qatar — Following, Not Leading

A Qatari family — a baby who was dying. I knew offering memory work was not appropriate here. My role was to support the parents and be present.

The baby's hair was falling out. The mother began quietly sweeping it to the side of the pillow — gathering it without saying a word. I said nothing. I simply offered a small envelope.

She looked at me. She was grateful. Sometimes the most important thing is noticing what someone is already doing — and making space for it.

Story: Presence Without Agenda

A five-year-old boy had drowned. Every day, his mother sat at the bedside and read from the Qur'an.

She shared her faith with me — openly, quietly. I listened. I asked questions because I genuinely wanted to understand, not because I needed to fill the space.

I could not offer her a project. There was nothing to fix and nothing to make.

What I could offer was the discipline of presence. Showing up. Sitting down. Staying — without redirecting, without resolving, without an agenda.

Some days we talked. Some days we didn't. She was not a task to manage. She was a mother. And I was there.

Active listening is not passive. It is a clinical skill — and often the most powerful intervention we have.

What the Team Can Do — Starting Now

Whether or not you have a child life specialist on your team, these principles can guide your work with children and families.

- Protect space for play and normalization — a child is still a child inside the hospital
- Ask families what matters to them — not just medically, but personally and culturally
- Include siblings intentionally — give them a role, not just a waiting room
- Create space for memory making — even something as simple as a photograph or a footprint
- Practice cultural humility — ask before assuming what a family would or wouldn't want
- Advocate for child life to be part of your palliative care team

Caring, Connecting, and Collaborating.

The principles of child life belong to all of us.

Thank you.

Loren Mirsky Piatkin | M.S., CCLS, GC-C, GCCA-C
@legacyandmemory | WhatsApp: +1-503-890-1393